Testimony of Christine Sullivan RE: Raised Bill No. 1088 Public Health Committee March 18, 2015

Senator Gerratana, Representative Ritter and Members of the Committee, my name is Christine Sullivan, I live in Woodbury and I am the Director of Education and Training for the University of Connecticut A.J. Pappanikou Center for Excellence in Developmental Disabilities Education, Research, and Service (CT UCEDD) located at Uconn Health in Farmington.

I also represent the CT UCEDD on the Connecticut Council on Developmental Disabilities, our sister agency also funded under the Federal Developmental Disabilities Assistance and Bill of Rights Act. The purpose of the DD Act is to assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, integration and inclusion in all facets of community life, through culturally competent programs.

As the director of education and training for the CT UCEDD, I want to assure the Committee members that the direction outlined in Raised Bill 1088, An Act Concerning Services for Individuals with Intellectual Disability. is consistent with everything we know about good practice for person's with disabilities and their families.

Most importantly, I am the proud mother of a daughter who is 14 and has an intellectual disability. It is for her future that I am compelled to testify today in favor of Raised Bill 1088, An Act Concerning Services for Individuals with Intellectual Disability.

The mission of the CT UCEDD is to provide interdisciplinary leadership on evidenced based practices and policies to ensure all of CT Citizens with Disabilities and their families fully participate in all facets of community life. The University of CT has supported this mission for the past 30 years.

In addition, we have a very active consumer advisory board who have adopted a vision for the CT UCEDD, and this serves as a guide for all our work. We believe that CT Citizens with Disabilities are valued citizens with opportunities and supports that allow them to be fully included, independent, productive and contributing members of society. We feel this vision is best met through a network of individualized community based services and supports for our citizens with disabilities and their families.

Our mission and vision compelled the CT UCEDD to join the Connecticut DD Council, the Connecticut Office of Protection and Advocacy and the CT ARC in launching the

2020 Campaign which calls upon the Governor and the Legislature to close the remaining state-operated institutions for persons with intellectual disabilities by the year 2020. We feel this campaign is based on the individual civil rights of persons with disabilities to live in communities, and to have full access to all facets of community life, which is our CT UCEDD's stated mission. As the director of education and training for the CT UCEDD, I want to assure the Committee members that the direction outlined in Raised Bill 1088, An Act Concerning Services for Individuals with Intellectual Disability is consistent with everything we, at the CT UCEDD, espouse as good practice for persons with disabilities and their families.

As a parent, I am very pleased that the Committee has introduced this bill. I do feel however, that it should require a plan and timeline for institutional closure. The plan and timeline should be detailed to ensure that the approximately 500 current residents of Connecticut's institutions are able to find suitable and appropriate homes in the community. This process must incorporate person-centered planning and must address the individual's and family members' specific concerns.

Connecticut, under your leadership, can accomplish what many other states have already done, and eliminate the segregated and antiquated system of congregate facilities. Funds saved from closing these institutions can be dedicated to building a community based infrastructure of services and supports that will enable the current residents of these institutions and other persons with intellectual and developmental disabilities to live, learn, work and play in their communities. Programs such as the CT UCEDD, and the other 2 state DD agencies, the Connecticut DD Council and the Office of Protection and Advocacy, have access to the research and knowledge to support the capacity building and system change for which will result from the passage of this bill.

My daughter is now 14 years old. She has been educated by our state public school system, as well as myself and my husband to expect that she will live in her community, enjoy the prospects of employment, earn a living, and be a contributing member of society. In no uncertain terms, she expects and is entitled to live an enviable life, just like you and I. However, as we discuss her transition to high school and begin to discuss life after the special education system, this may not be possible under our current system — at least until a tragedy occurs or we, her parents, become incapacitated. And I can assure you that she may only require minimal support to live on her own. And if she is not allowed this freedom, it will be a tragedy of all that has gone before to make her the independent young lady she already is.

While decisions were made in the past which did not reflect inclusive choices for individuals with intellectual or developmental disabilities, I feel as a parent, Connecticut can no longer wait for this issue to slowly go away on its own.

As a parent, I am speaking in support Raised Bill 1088, An Act Concerning Services for Individuals with Intellectual Disability. As a parent I also recommend that the Act include a clear and definitive agreement to close all of Connecticut's institutions by 2020. The cost savings should be redirected toward the development of safe and effective self-directed home and community-based services and supports for people with intellectual and developmental disabilities such as my daughter.

Thank you for the opportunity to testify today.